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ABSTRACT

Focusing on relationships between children's behavioral responses and family characteristics, this exploratory, descriptive, and retrospective study investigated bereaved children's responses to the death of a sibling from cancer and examines those responses in relationship to selected individual, situational, and environmental characteristics. Participating in the study were 34 two-parent families from the United States and Canada who had had a child die from cancer within 3 years from the time of data collection and who had a surviving child between 6 and 16 years of age. The Child Behavior Checklist was used to measure behavior problems and competencies reported for bereaved children, and the Family Environment Scale was used to assess dimensions of family social climate. Content analysis of interview data preceded the coding of all data for quantitative analysis. It was found that internalizing and externalizing behaviors correlated negatively with social status, whereas social competence correlated positively with social status. Both internalizing and externalizing behaviors were related negatively to family cohesion, and lower internalizing scores were related to intellectual/cultural orientation, active/recreational orientation, and moral/religious emphasis. Implications of the results were pointed out for nurses who work with children and families in situations of long term illness and death. (RH)

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CHILDREN'S RESPONSES FOLLOWING A SIBLING'S DEATH:
ROLE OF FAMILY AND COMMUNITY ENVIRONMENTS

A Paper Presented at the
Association for the Care of Children's Health
19th Annual Conference

May 28, 1984

Houston, Texas

by

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Overall Purpose

The overall purpose of this study was to investigate behavioral responses of bereaved children to the death of a sibling from cancer and to examine these responses in relation to selected individual, situational, and environmental characteristics. The focus of this paper is on the relationships between the children's behavioral responses and specific family characteristics of the family environment.

Background and Rationale

The concepts of 'adaptation to loss' and 'environment' were among those that formed the conceptual framework for this study, a basic premise being that coping and adaptation cannot be studied apart from the environmental context in which they occur.

Children's Responses to Sibling Death

The literature provides evidence that children's adaptation to the loss of a sibling can result in a wide range of possible responses. Several researchers reported that a majority of the children in their samples demonstrated significant behavior problems or required psychiatric intervention following the death of a sibling.^{1,2,3} Other investigators, however, reported no

obvious increase in problems among surviving siblings.^{4,5,6} Discrepancies in these sets of findings may be due to differences in the nature of the samples or in the definitions of what constitutes behavior problems. Only one⁷ study used comparison groups or a valid standardized tool to compare the siblings' behavior to specified norms. Further, some studies² of childhood bereavement have discussed the potential significance of family environmental variables for adaptation in childhood bereavement, but few studies have explored this relationship.

Family Environment

The family environment is one aspect of the larger context in which adaptation to loss occurs. It is defined as the emotional atmosphere occurring within the family system, created by the interaction of the individual family members and directly affecting the behavior of individuals within the setting.

In situations of childhood adaptation, the family environment is especially pertinent because the child is so dependent upon his family. For example, his immaturity prevents him from going elsewhere for advice or assistance in the same ways that adult family members can make use of extrafamilial resources. The enormous influence of family environmental variables on children's responses to situations of loss has been implied in

the literature,^{2,3} yet few studies of childhood bereavement have explored this relationship.

Methods

This study was an exploratory, descriptive, and retrospective one utilizing in-depth semi-structured interviews.

Sample

The sample was a non-probability one and participation was strictly voluntary. Families were selected for participation based on two criteria:

- 1) the family had had a child die from cancer within the past three years (not less than two months, and not more than 36 months) from the time of data collection; and
- 2) the family had a surviving child who, at the time of data collection, was between 6 and 16 years of age.

Families were obtained from several sources including two pediatric hematology-oncology clinics; a pediatric oncologist; and a chapter of the Candlelighters' Association. The four sources yielded 39 prospective families of whom three could not be located. The remaining 36 families agreed to participate in the study, but two subsequently withdrew. Thirty-four families

therefore comprised the sample. For the purposes of the study, data were analyzed for only one surviving child in each family and the data used were based on the responses of the mothers only because mothers' data were available for all families. In families with more than one surviving child, the child selected for inclusion was the one closest in age to the deceased child. Further analysis of data relating to the other siblings is currently under way.

Instruments and Measurement

Child Behavior Checklist

The Child Behavior Checklist (Achenbach and Edelbrock^{8,9,10}) was used to measure the behavior problems and competencies reported for the bereaved children. The CBCL obtains parents' reports of both behavior problems and competencies of their 4-16-year-old children in a standardized format. It provides four summary scores: 1) Total Behavior Problem Scores; 2) Total Internalizing Scores (problems within the self, such as "withdrawn"); 3) Total Externalizing Scores (problems of conflict with the outside world, such as "argues a lot" or "disobedient"); and 4) Total Social Competency Scores. Behavioral competencies refer to school performance; the amount and quality of participation in sports, hobbies, and chores; and social relationships. The CBCL

provides standardized norms for age and sex. It demonstrates test-retest reliability¹⁰ and discriminative reliability.¹¹

Family Environment Scale

The Family Environment Scale (FES)¹² was used to assess dimensions of the social climates of families. The scale uses true-false responses to describe ten family characteristics and provides scores ranging from 0-9 for each subscale. Test statistics indicate that the internal consistencies for subscales are all in an acceptable range and test-retest reliability has been demonstrated.¹²

Data Analysis

Content analysis of interview data preceded the coding of all data for quantitative analysis using the SPSS Computer Package.¹³ For purposes of analysis, summary CBCL scores and subscale FES scores were used. Correlational techniques were utilized to look at relationships among variables.

Results

Characteristics of the Sample

The families who participated in this study resided in four geographic areas within both the United States and Canada,

including Eastern and Western Washington, Southern Arizona, and Central Alberta.

The majority of families were two-parent families. The average age of the parents was 39 1/2 years, and the majority were Protestant and Caucasian. Many had at least some college education and they were employed in a wide range of occupations.

With regard to the children who died, the majority were male and were between 1 and 19 years old at the time of their death. The majority of the surviving children studied were female, and by design, they were between 6 and 16 years of age.

Characteristics of the Illness of the Deceased Children

The children who died from their illness had a variety of cancers, though nearly equal numbers had either leukemia or solid tumors. Ten children had been ill for less than one year, 11 were ill for between one and two years, and 13 had had an illness duration of greater than two years. The time which had elapsed since the time of the child's death ranged from 2 to 36 months.

Behavior Scores for Bereaved Children

The sums of behavior for each of the summary scores were transformed to normalized t-scores and compared with the mean normal t-score of 50 with a standard deviation of 10.¹⁰ The

means and standard deviations for the summary scores of this sample are presented in Table 1.

The means for behavior problem scores of bereaved children were all higher than the standardized mean of 50. Conversely, the sample mean for the Total Social Competence scores was less than the standardized mean. The bereaved children in this study demonstrated more behavior problems, especially internalizing problems, and less socially competent behavior than the normal population of children. Comparisons between the mean scores for bereaved children and for the standardized normal population indicated that there were significant differences for both Internalizing Behaviors and for Social Competence Behaviors.

Behavior and Family Characteristics

The summary behavior scores were correlated with selected family characteristics. Only three statistically significant correlations were found. Both Internalizing behaviors ($r = -.49$, $p < .01$) and Externalizing behaviors ($r = -.35$, $p < .05$) correlated negatively with social status, and Social Competence correlated positively ($r = .36$, $p < .05$) with social status. In families of higher social status, bereaved children demonstrated fewer behavior problems and more social competencies.

Behavior and Family Environment

Various behavior scores were found to relate significantly to four of the family environment subscales. Both Internalizing ($r = -.54$, $p < .001$) and Externalizing ($r = -.45$, $p < .01$) behaviors related negatively to Cohesion. That is, the greater the degree of commitment, help, and support family members provided for one another, the fewer the numbers of both Internalizing and Externalizing behaviors reported for the surviving children.

Lower Internalizing behavior scores were found to be significantly related to three other FES subscales. These subscales were Intellectual-Cultural Orientation, Active-Recreational Orientation, and Moral-Religious Emphasis. This suggestion is supported by the finding that social competence scores were greater in the children whose families scored higher on both the Active-Recreational Orientation and Intellectual-Cultural Orientation subscales.

The relationship between the children's behavior scores and the families' participation in activities outside of the home is an interesting one and requires further investigation with regard to the support received as a result of such participation. The qualitative data provided an indication that the families' scores on the Active-Recreational Orientation subscale and the Intellectual-Cultural Orientation subscale are related to the number of friends and relatives and the type of support received from them.

For example, the family with the lowest score (which was 1) on the Active-Recreational Orientation subscale also had the lowest score (which was 2) on the Intellectual-Cultural Orientation subscale. The situation in this family was as follows:

They had moved to a western city from the east coast four years prior to the interview. Their first residence in the new city was in the upstairs of a house; the owners of the house lived downstairs and although "the owners were very good to us when Ben [the deceased child] was first sick", they had little contact. Shortly after Ben's diagnosis was made, the family moved to a low rental townhouse where "We don't have much to do with folks here." The family had few friends. Their only visitor when Ben died was a minister they had called using the Yellow Pages to come to help with the funeral. The mother could not recall if any of Sarah's (surviving child) friends were at the funeral. Extended family members were minimal: "We don't have no family really - Sarah's half brother moved out here when Ben died - he's all we've got."

Furthermore, the families' participation in activities and with friends was also related to the behavior scores of the surviving children. The surviving daughter in this family had many behavior problems since her brother's death and she was the one child in the whole study who had dropped out of school. Sarah's Total Behavior Problem score was at the 90th percentile and her Social Competency score ranked at a percentile of 1.5.

In contrast to this family is the family who scored highest (nine) on both the Intellectual-Cultural subscale and the Active-Recreational subscale. The mother said:

My nephew [who is 22 years old] came as soon as Rhonda died. His own brother died last year so he really can help the boys [surviving child and his brother]. He's so good -- he helps cook and has built a new room for us in the basement. He's so good with the boys -- he really is good for us all. My aunt was here when Rhonda was sick, and so was my best friend. My brother is a priest and he comes as much as he can -- you know, since Rhonda has gone, we've been all alone only one night. There is someone here to help all the time. My friends at school are good too -- they know Rhonda because I used her as a subject for a project at school -- there were loads of people at the funeral -- all of the boys' friends were there and so were their teachers.

The surviving child in this family had very few behavior problems and he was doing extremely well in school and in his relationships with other people. His Total Behavior Problem score ranked at the 19th percentile and his Social Competency score at the 88th percentile. Areas requiring further investigation then have to do with family participation in activities outside of the home, the support received from such participation, and the relationship of these two variables to the bereavement outcomes of the children.

Implications for Nursing Practice

This study evolved from nursing contact with children and families; therefore, the implications of the study are reported with nurses in mind. However, the implications can be inter-

preted as useful for other members of the health care team as well.

The results of this study suggest implications for nurses who work with children and their families in situations of long-term illness and death. The findings gave evidence that the death of a brother or sister has significant impact upon the surviving children. Their response is evident in changes in their behavior. Nurses or others who are knowledgeable about these responses can offer guidance to parents about what grief reactions to expect in their children. They can offer reassurance about such reactions when they occur and they can observe for patterns of behavior which may be indicative of psychopathology and refer such children for additional assistance.

Cohesion in the families was significantly related to lower behavior problem scores in the children. This finding implies that health care professionals need to reinforce positively those families who are cohesive, and to develop methods of facilitating cohesion within those families who are less supportive of one another. Changing institutional practices such as having information sessions with family units as a supplement to conferences held just with parents serves as one example of what could be done to encourage family cohesion.

The findings also indicated that families who had greater participation in a variety of activities outside the home had

grieving children with fewer behavior problems. Often, under the duress of caring for a terminally ill child and during grief, families withdraw from activities outside of the home. Knowing that contact with others serves a therapeutic purpose, nurses and others can encourage continued participation and can even initiate such activity in cases where it is lacking. Having available concrete information about support groups, arranging for visits from people associated with the families' external activities, and acknowledging the contribution of supportive outsiders are specific actions for nurses working with bereaved children and their families. Finally, emphasizing the family as the unit of service facilitates the directing of attention specifically to the family environmental variables which impact upon the grief responses of the bereaved child.

Table 1
Characteristics of the Children

Characteristic	Deceased Children		Surviving Children	
	N	%	N	%
<u>Sex</u>				
Male	23	67.6	13	38.2
Female	11	32.4	21	61.8
<u>Age in Years</u>				
1 to 5	8	23.5	0	0
6 to 8	4	11.8	7	20.6
9 to 11	7	20.6	7	20.6
12 to 14	12	35.3	13	38.2
15 to 19	3	8.8	7	20.6
<u>Ordinal Position</u>				
Oldest	9	26.5	11	32.4
Middle	10	29.4	13	38.2
Youngest	15	44.1	10	29.4
<u>Grade in School</u>				
Grade 1 to 3	-	-	8	23.5
Grade 4 to 6	-	-	9	26.5
Grade 7 to 9	-	-	10	29.4
Grade 10 to 12	-	-	6	17.7
Not in School	-	-	1	2.9

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